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ABSTRACT

The purpose of the conference summarized here was to provide a multidisciplinary examination of the critical service needs of youth who are profoundly/multiply handicapped with deaf-blindness and who are old enough to be leaving the education system, and to recommend strategies for providing high quality comprehensive transition services for the youth and their families. Four conference working groups focused on: residential services and options, independent living and employment options, recreation and leisure options, and health and psychosocial services. The groups considered the conference presentations and discussions, identified the issues, and formulated recommendations for programs and policy. A synthesis of the four working group reports is presented, covering: definition of the population; philosophical premises; characteristics of high-quality programs and services; and issues and recommendations in the areas of attitudes and advocacy, personnel training, program accessibility, parent/family involvement, policy- and agency-related issues, and the problem of working from a limited knowledge base. Conclusions are drawn concerning transition and the quality of life, the individual in the context of family and environment, the state of the art of services, staff and training, and dissemination and advocacy. (JDD)

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SUMMARY

Summary, Conclusions, Recommendations, and Implications of the Conference: Purpose and Format

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EC 211 071

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Purpose and Format of the Conference

The National Conference on the Transition of Profoundly/Multiply Handicapped Deaf-Blind Youth was a collaborative effort of Special Education Programs (U. S. Department of Education), Division of Maternal and Child Health Programs (U. S. Department of Health and Human Services), The Association for Persons with Severe Handicaps (TASH) Technical Assistance Project, and the Helen Keller National Center Technical Assistance Center (TAC). The overall purpose of the conference was to provide a multidisciplinary examination of the critical service needs of youth who are profoundly/multiply handicapped with deaf-blindness and who are old enough to be leaving the education system, and to recommend strategies for providing high quality comprehensive transition services for the youth and their families.

The objectives were as follows:

1. Examine the current transition service needs of youth with deaf-blindness and other profound handicaps and their families,
2. Describe the "state of the art" of available services,
3. Identify the service gaps and issues involved in providing high-quality transition services,
4. Recommend strategies for establishing optimal comprehensive transition services for youth who are profoundly/multiply handicapped with deaf-blindness and for the families of this population.

In examining comprehensive transition services, a major paper and two responses were presented in each of four areas:

1. residential services and options,
2. independent living and employment options,
3. recreation and leisure options,
4. health and psychosocial services

The presenters and respondents were asked to discuss the following:

1. the service needs of this population and their families;
2. the "state of the art" of available services for adolescents and adults with deaf-blindness and other profound handicaps;
3. the gaps in the services;
4. models and options to address the gaps in providing high-quality services for these youth and their families;
5. the needs of the systems providing services for this population, including interagency efforts;
6. the necessary support systems, including financing;
7. the implications for earlier education;
8. the role and involvement of parents and families.

The conference was designed as a "working conference" of approximately fifty invited participants with diverse backgrounds, including an interdisciplinary group of professionals in the field, policy makers, agency personnel and parents. Participants were drawn from education, rehabilitation services, health, and social service areas.

Each participant was preassigned to one of four groups which corresponded to the topic areas. The function of the groups was to consider the presentations and discussions, to identify the issues, and to formulate recommendations for program and policy. Each group spent a full day in a work session, and presented a group report the following morning. Summaries of the group reports are included in this book in their respective chapters.

Synthesis of Working Group Reports

Population

One issue that emerged in defining the population for the small working groups was whether the focus should be specifically on individuals who are deaf and blind, or whether the focus should encompass a broader population of individuals with profound multiple handicaps. The consensus was that because of the unique specialized needs of individuals with profound multiple sensory impairments, the working groups would focus specifically on persons who are profoundly/multiply handicapped with deaf-blindness. However, the groups agreed that the problems of accessibility to community-based services, the need to consider the individual in designing programs, and many of the issues and recommendations developed specifically for this population apply as well for all persons with profound handicaps.

The population was defined as a low-incidence population of individuals who are physiologically or functionally deaf-blind with additional profoundly handicapping conditions such as profound mental retardation and/or physical disabilities.

Additional characteristics of this population would include some or all of the following:

1. have developed only very limited communication skills;
2. lack independent mobility skills;
3. will need assistance in daily living skills, including feeding and toileting;
4. may exhibit severe behavioral disorders, including self-abusive and aggressive behavior:
   a. will require intensive, lifelong services such as medical care and physical, occupational, speech, and language therapies;
   b. will require lifelong assistance with skills and activities for integration in normal community environments.

The population includes those individuals described above who are of the age to be leaving, or have recently left, the mandated services of the public education system and are moving into the adult services systems.

Additionally, although not necessarily secondarily, the families of the target population were considered a significant part of the focus of this conference.

Philosophical Premises—Belief Statements

In considering what constitutes quality services for profoundly/multiply handicapped deaf-blind individuals, the working groups articulated a series of belief statements, creating the ethical framework, or ethos, of quality services. A synthesis of those belief statements follows:

1. All individuals, regardless of severity of handicapping conditions, have a fundamental right to individual dignity and the pursuit of happiness. They should be viewed as individuals, with individual rights, capabilities, and needs.
2. These individuals should have access to an array of adult services, with zero exclusion for eligibility in the adult services system, as in the education system.
3. Services provided for this population should aim toward full integration in the community and should enhance the quality of life of the individual, as well as his/her family, and include an array of options and choices to meet the individual's particular needs, desires, and interests.
4. Determination of any of the service options should be based on the individual's needs, abilities, and potential, and provide for continuing skill development, training, and education.
5. Services should be provided in settings that will foster interaction with others,

especially nonhandicapped individuals, as much as possible, and with and by individuals who are caring, respectful, and can overcome the communication barrier.

6. All individuals can benefit from and should have access to community-based services which provide for a small "homelike" residential arrangement as well as valued daily activities including vocational and employment options and recreation and leisure activities.
7. Profoundly multiply handicapped deaf-blind individuals, as other individuals, should have access to the benefits of our society, including comprehensive high-quality care of their physical and psychosocial needs.
8. In providing comprehensive transition services, residential options, work/employment options, recreation/leisure activities, and health and psychosocial services must be viewed as interdependent aspects of a person's life and cannot be considered as isolated services or foci.
9. Preparation for community-based independent living and the world of work should begin at the earliest age possible, and be designed to assist the individual and family to develop expectations, attitudes, skills, and experiences leading to integration in the community.

Program Approach - Characteristics

In defining high-quality programs/services for this population, which would reflect the ethos and values of the "belief statements," the following program approach and/or characteristics are delineated.

1. Programs/services for this population should recognize the unique communication and mobility problems of this population and be designed to meet the individualized needs of the client and his/her family, including options and choices for
   a. community-based living alternatives;
   b. employment/work options including supported work in business and industry;
   c. recreation and leisure activities on a daily basis;
   d. comprehensive health and psychosocial services that are individualized, are appropriate, promote wellness, and include support services for the families;
   e. full array of support services such as transportation, in-home respite care, and benefits.
2. Programs should occur in natural settings and foster continuing education, training, and skill development in communication, mobility, and self-care. Skill development should be future-oriented and directed toward lifelong use.
3. In recognition of the interdependence of the various components of comprehensive services, and to gain optimum benefit, an individualized case management system should be implemented to gain access to and coordinate the services across systems, develop assessment mechanisms, keep records, and share information, as appropriate, with other care providers.
4. All programs and program decisions should include a significant role for the parents and families. Not only is parent/family support essential for the success of community-based services, their expertise, knowledge, and understanding of the individual can enhance the potential for success. Programs and services must also consider and be responsive to the family's needs, interests, and preferences.
5. Personnel providing services for this population should be well trained and have skills in alternative communication systems to reduce the handicapped individual's isolation and improve his/her social integration.
6. Personnel should also be trained to diagnose, assess, and design programs that take into account the individual's auditory and visual ability, communications approach and skills, orientation and mobility training, self-preservation, and safety issues, and nonaversive behavior instruction.
7. Health issues must be considered in all living, work, and recreation environments,

and should be considered as part of the overall service plan.

8. Programs and services should have an evaluation component which reflects the values of the program and the quality-of-life issues for the individuals.

Issues and Recommendations

Developing and implementing high quality community-based transition services for this population presents many challenges and barriers. This section identifies a number of issues to be addressed and recommendations for improving transition services for individuals with deaf-blindness and other profound handicaps. While the list may seem extensive, it is not exhaustive.

Attitudes and Advocacy

Low public awareness, negative attitudes, and limited advocacy efforts constitute major barriers to providing high-quality, community-based services for individuals who are profoundly/multiply handicapped with deaf-blindness. Often the key to success of community-based programs depends on the attitudes, willingness, and support of local service agencies, vendors, businesses, and neighborhood residents. Yet for this population, there is low public awareness and understanding, low esteem, and low expectations, particularly regarding their potential to function in integrated community settings. Additionally, many professionals and service providers in the field hold limited expectations for this population, with somewhat negative attitudes toward their ability to be successful in community-based settings.

In order to improve community-based services, it will be essential to improve the advocacy efforts on behalf of this population and to improve the public awareness, understanding and expectations. Advocates for services to persons with profound multiple handicaps including deafness and blindness should form alliances with advocates for other low-incidence populations in order to increase their strength in advocating high-quality services. The advocacy efforts need to focus on obtaining new and improved services for this population, as well as gaining access to existing community-based services from which these individuals traditionally have been excluded.

Personnel - Training

There is a shortage of well-trained personnel including administrators, professionals, and paraprofessionals who can provide high-quality community-based services for this population. The shortage is evident in all areas such as residential, employment, recreation/leisure, and health/psychosocial, and at all levels, including state, county, and local agencies, programs, schools, parks, and health care agencies.

There is a lack of commitment from the higher education community, and a lack of incentive from the federal level to prepare personnel to provide services to low-incidence populations. Preservice training programs are needed to recruit, train, and retain new personnel, including leadership as well as service providers, for comprehensive, community-based services for this population. Also, there is need for inservice training for personnel who are providing services, but need to expand their range of competencies in areas such as the following:

1. developing specific competencies for working with individuals with deaf-blindness and other profound handicaps;
2. developing competencies for new roles such as that of job coach, recreation coach, therapeutic recreation specialist, community health care provider, community residence manager;
3. developing competencies for new settings, for example, staff who previously worked in segregated settings now may work in community-based, integrated settings.

Staff providing services for this population must be well trained, particularly in utilizing alternative communication systems and in understanding sensory deficits. New roles related to community-based services, that of job coach or recreation coach, need to be demonstrated with this population; the specific role competencies need to be identified, and the information disseminated.

Federal incentives are needed to support both preservice and inservice programs to encourage the recruitment, training, or retraining of qualified personnel for services to this population. Training programs should reflect the comprehensiveness of needed services and focus on a wide range of roles including those of leaders, teachers, counselors, health care providers, direct service providers, and new roles associated with community-based services.

Health care professionals and service providers need interdisciplinary training which equips them to provide a full range of health services. The training needs to include medical issues, psychosocial issues, and the specific needs of this population such as communication systems and adaptive aids and devices.

Program Accessibility

Programs and services for those who are profoundly/multiply handicapped with deaf-blindness should be designed to enable the individual to move as much as possible toward settings with nonhandicapped peers.

Individuals with profound multiple handicaps, as well as their families, need to be prepared for community-based living. Preparation, including education and skills training, should begin as early as possible, at least three years before the individual exits from the education system.

Many of the comprehensive community-based services are either not available to this population or are limited by financial issues, fiscal constraints of the family or logistical issues.

Community-based services not only must be available but also accessible. The lack of adequate and appropriate transportation often precludes access to some services. Another barrier often cited is the safety factor, with a need to strike a balance between the concern of the individual's safety against the risk of newer services.

Ongoing comprehensive services will be necessary to help these individuals to live in the community, but there has been a lack of commitment from agencies to provide the long-term funding for community-based services for the individual and for a system of supports for the family. Agencies need to recognize the importance and interdependence of comprehensive services, and provide program support for the community-based living, work, recreation/leisure, and health care. The programs should reflect the unique needs of this population, particularly with regard to communication systems.

Parent/Family Involvement

Providing services to this population must take into account parent/family needs, preferences, desires, and value systems. Parents and families need to be involved to enlist their support as well as their expertise, in all aspects and at every level, in providing comprehensive services for individuals with profoundly handicapping deafness and blindness. They need to be involved in decisions regarding the education and training of the individual with handicaps, as well as in the placement in community services. In order to strengthen the parent/family role, parents need to be provided with full information on options and choices open to them and to the handicapped child.

Parents/families often lack information on the range of services, including community-based services that are, or can be, available to them. Additionally, there is limited evidence to assure parents of the viability and benefits of community-based services for this profoundly handicapped population. Thus, lacking the necessary information on alternatives and the concomitant support system for the family, a concern for the care

and safety of the handicapped individuals, and in consideration of the impact on other family members, parents frequently choose the more traditional, familiar services.

In addition to providing a support system for families, it is important to assist parents and families in increasing their knowledge, understanding, and acceptance of current trends in community-based transition services, to increase their expectations and aspirations for their handicapped family member, and to enlist their expertise and support in obtaining high-quality community-based services for their young adults.

There needs to be a nationwide strategy and commitment for parent/family involvement in transition services for this group. Models of comprehensive family support systems need to be developed and demonstrated to assist the parent/family involvement.

Policy- and Agency-Related Issues

Historically, there has been a reliance on institutions and segregated settings to provide services to individuals who are profoundly/multiply handicapped with deaf-blindness. With the increasing trend toward de-institutionalization, there has been an increase in the numbers and kinds of community-based services. However, because of the severity of the handicapping conditions and magnitude of necessary specialized services, this population generally has been excluded from those programs.

Public policy should reflect a commitment to providing comprehensive, high-quality, community-based transition services for all individuals, regardless of severity of handicap. The services should aim to foster independence and enhance the individual's quality of life. Financial commitments at the federal and state levels are essential as support to policy statements.

There is no overall mandate, with zero exclusions, to provide comprehensive adult services for individuals with handicaps. Adult service agencies are generally limited by laws and regulations in determining clients' eligibility for the services, including age limits, kinds of services supported, and length of time services can be provided. Generally, the eligibility requirements for community-based services have excluded populations requiring long-term comprehensive care.

Federal agencies and, in turn, state and local agencies need to recognize the newer, community-based services as viable options, eligible for support and funding. For example, the supported-work concept should be accepted by the Rehabilitation Services agencies as a viable "closure"; additionally, eligibility requirements of these agencies need to be expanded to include individuals with profound multiple handicaps of deaf-blindness who require comprehensive long-term care.

Because of the severity of the handicap, and the complexity of needed services, interagency efforts are essential, with case management provided by the lead agency. However, for the most part, there is no identified "lead agency" to provide leadership and coordinate services for this population. The interagency coordination is needed at all levels, including the federal level. The federal agencies such as Special Education Programs, Rehabilitation Services Administration, and Maternal and Child Health Programs should continue their collaborative efforts in support of services for these individuals. Further, their efforts should be expanded to include other relevant agencies such as the Administration for Developmental Disabilities, and National Institute for Mental Health. An interagency group should develop definitions for high quality comprehensive services, and guidelines to overcome agency barriers in providing the services.

Limited Knowledge Base

While many of the community-based services have been available to populations with other handicapping conditions, there is limited experience related to community-based services for those who are profoundly/multiply handicapped with deaf-blindness. The lack of knowledge presents a barrier in convincing parents/families, service providers,

agency personnel, and policy makers of the viability of community-based services for these individuals and their families. There is need to define quality comprehensive services, identify models of quality or successful programs, delineate salient features and characteristics or best practices, and disseminate the information widely. Dissemination efforts should include information on high-quality community-based services as well as systems change models, including interagency-interdisciplinary models of service programs.

Additionally, research is needed to advance the knowledge base on understanding what kinds of services are viable and necessary for this population and their families. Issues such as client success in integrated settings, family involvement, and support services all need further study.

The federal government should provide fiscal support for further demonstration programs and for dissemination of information.

Conclusions and Implications

Transition and the Quality of Life

The basic premise of the conference was that while individuals with deaf-blindness and other profound handicaps may require lifelong care, they still can benefit from and should have full access to community-based services in the least restricted environment, and, with nonhandicapped peers, to the greatest possible extent. Thus, those services which aim to facilitate the transition of these individuals from education to adult living should have community integration as the goal, with quality of life as a major concern. The transition process should include opportunities to continue the learning and skill development that will enhance their living and independence; it should include options, alternatives and opportunities to make choices and decisions; and it should make available the information necessary for the individuals and their families to make informed choices.

Transition, one of the most overused words of recent years, has taken on many meanings. Perhaps the most common use of the word in reference to youth with handicapping conditions is to mean the "bridge between school and adult years," often viewed as "school to employment." While employment is a significant part, or outcome, of the transition process, it is just that: one part.

Transition for youth with deaf-blindness and other profound handicaps is a comprehensive process and should encompass a wide array of services. It is a process concerned with the total life of the individual, with facilitation of independent living to the greatest possible extent. The transition process must include planning and services for residential or living arrangements; employment options and ongoing building of skills; opportunities for recreation and leisure, as individuals or in groups; the health and social services to attend to the wellness of the individuals; and the necessary support services, such as transportation and respite care to make the other services accessible.

In the transition process, the primary focus should be on the individual, not on the services; programs should be developed to address the individual's needs rather than to fit the individual into the framework of available services. It is clear that the various aspects of transition services are interrelated and interdependent, just as the components of a person's life are interrelated and interdependent. The services need to be coordinated to form an integrated, comprehensive whole.

The Individual in Context of Family and Environment

The individual with deaf-blindness and other profound handicaps must be viewed in the context of his/her environment—the human environment as well as the physical environment. The individual is in constant interaction with his/her human environment, particularly with parents, family members, service providers, care givers, and others

in the community. It is important to consider the environment when providing services, and provide the necessary support system to create a positive one.

Parents and families play a crucial role in the transition process, not only for the support and care which they provide, but also for their knowledge and expertise as their child moves into adult life. Parents often function as "case manager" for the child and should have a significant role in the planning and decision making at every level of the transition process.

In order to make informed decisions, parents must be provided with full and accurate information on the child's abilities and limitations, as well as the range of options and services available. The family's interests, needs, and desires must be considered in determining services and placements for the individual with handicaps. Further, a support system, including financial, social services, transportation, and respite care must be provided to enable families to maintain the young person in the community.

State of the Art of Services

In the past decade there has been great progress in providing high-quality, community-based services for persons with handicaps. However, these community-based services, for the most part, have not been available to persons with deaf-blindness and other profound handicaps. The state of the art of community-based services has not been advanced to the point of serving those persons with the most severe handicapping conditions. There may be a number of reasons why this is so. First, there has been a heavy reliance on traditional institutional settings for services to this population. Another reason may be that many service providers, as well as the general public, do not believe that this population can benefit from or be serviced in settings which are integrated in the community. Public policy and eligibility requirements for adult services do not provide a commitment to the long-term care and funding for community-based services for this population. Also, parents and families lacking information on the options and alternatives which could be available, and lacking evidence regarding the benefits and safety of community-based services, tend to rely on the traditional, well-known arrangements.

The presented papers and responses at the conference illustrated some exemplary community-based programs—programs which had been well developed, implemented, evaluated, and documented. While these programs represented state of the art in services, none were focused directly on individuals with deaf-blindness and other profound handicaps. It is clear that we have the technology for community-based services: The challenge is to build on the extant knowledge base and advance the state of the art to include this population.

Efforts need to be made to change public policy so that community-based services are accepted as viable options, with full support, for individuals who need comprehensive lifelong care. Providing comprehensive transition services requires a sharing of responsibility and resources between and among agencies at all levels—federal, state, and local—and among parents and families, local service providers, and community residents. Eligibility requirements for service may need to be altered, and agency boundaries may need to be crossed to provide coordinated services and support. Further, federal agencies should require states to identify a "lead agency" to be responsible for coordinating services among and between agencies, to provide the leadership in negotiating between agencies, and to overcome turf barriers in providing coordinated, comprehensive services.

Staff and Training

Staff providing services to this population need to be well trained for a range of roles including those of teachers, counselors, and administrators, as well as for new roles such as job coach and community residence managers. Staff need to understand the

effects of profoundly handicapping conditions, have competency in alternative communication systems, and knowledge of the most advanced state of the art of community-based service.

In addition to new skills and competencies, providing services in community-based settings places new demands and expectations on staff who have been working in the more traditional institutional settings. For some, it may mean functioning in new ways and, in a sense, renegotiating their roles. In working as part of multidisciplinary teams, it may mean overcoming turf barriers and collaborating with other agencies, or it may mean working in collaboration with parents and family members as full partners.

In order to ensure quality transition services for youth with deaf-blindness and other profound handicaps, it is necessary to encourage new training programs such as preservice training programs to recruit new staff at all levels to the field, and inservice training programs for those service providers who need, or want, to extend their range of competencies. It is essential that the federal government provide incentives for the higher education community to prepare staff to work with low-incidence populations.

Dissemination and Advocacy

With a limited base of knowledge, we need to identify and document the best of the technology, the art and science of serving those with deaf-blindness and other profound handicaps. There is need to identify or develop some exemplary models, identify the salient or critical features, and disseminate information widely for the purposes of illustrating what can be done, as well as how this population can benefit from these services.

Advocacy efforts on behalf of this low-incidence population need to be strengthened in order to obtain new or improved services. One means of accomplishing this would be to build coalitions with other advocacy groups. While recognizing the specialized needs of those individuals with deaf-blindness and the need to maintain specialized services, advocacy groups can work together to try to eliminate sharp barriers between those with deaf-blindness and other populations. With the increased strength of their combined efforts, advocacy groups can work toward improving services for all youth and adults with profound multiple handicaps, with a goal of continuing the guarantee of rights to services after reaching age 22 and throughout the adult years.

Concluding Statement

Transition, a word with many meanings, is used in this book, and was used in the conference which served as the basis for this book, to refer to the passage from school-age years to adult living. The population of concern are those individuals with deaf-blindness and other profound handicaps.

An underlying theme of the conference and a commitment of the participants is that transition is an ongoing process which should lead to community integration for the individual, regardless of severity of handicapping condition. It is a process concerned with the total life of the individual, with programs and services determined on the basis of the individual's abilities as well as disabilities, the individual's strengths as well as needs. It is a process that views the individual in the context of his/her environment--human and physical--and aims to improve the individual's quality of life in that environment. It is an outcome-oriented process that includes an array of services leading to options and choices in community-based living arrangements, work opportunities, recreation and leisure activities, and the health and psychosocial services, all of which are interrelated and interdependent just as the aspects of a person's life are interrelated and interdependent. It is a process that delivers services to achieve those outcomes in a comprehensive, coordinated manner. And, it also is also a process that considers the individuals' parents, families, and community and provides a support system for them as well.

The conference and this book have focused on the specialized needs of persons with profound multiple handicaps of deaf-blindness. However, the results of the conference indicate that many of the problems and issues involved in accessibility to high-quality programs, the comprehensiveness of needed services for the individuals as well as their families, and the recommendations for improving transition services that lead to the individual's integration in the community apply as well to all individuals with profound handicaps.

Advancing the state of the art of community-based services to include those individuals with deaf-blindness and other profound handicaps presents new demands and challenges for all of us who are the policy makers, the professionals and service providers, the parents and families, and the community. It requires us to think and work in new ways, to cross the boundaries of classrooms and agencies, to interact in new ways with parents, families, and personnel in other systems, and even to redefine our roles in providing services to individuals with profound handicaps. In a sense, it is a time of transition for us as well.